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ABSTRACT

The paper was written to document the importance and efficacy of comprehensive early intervention services for children with special needs and their families; to serve as a resource to a wide range of agencies, organizations and individuals concerned about the needs of special needs children and the families; and to advocate support at all government levels for providing accessible, continuous, high quality services beginning at birth for children with special needs and their families. Section I includes reviews of research which demonstrates the effectiveness of intervention programs and their impact on the development of very young handicapped children and on infants and toddlers at risk. Early intervention research findings are reported in relation to motor development, emotional and social development, language development, cognitive development, specific populations (such as the mentally retarded and severely/profoundly handicapped), and newborns. Section II describes the effect of services on the family, identified family service needs, and the rationale for the participation of families in programs for handicapped infants and toddlers. A third section shows data on the costs and cost effectiveness of intervention programs for children aged birth to 3 years, and the fourth section outlines the characteristics of a comprehensive service delivery system followed by specific recommendations for action at local, state, and federal levels. Tables and charts offer statistical data on special education costs. (Author/SB)

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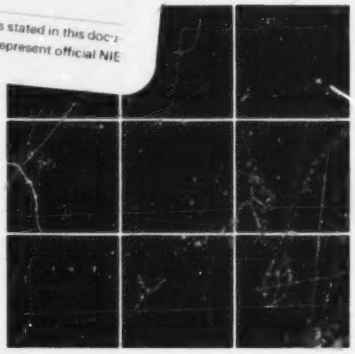

# Early Intervention for Children With Special Needs and Their Families

## Findings and Recommendations

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# EARLY INTERVENTION

# FOR

# CHILDREN WITH SPECIAL NEEDS AND THEIR FAMILIES

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for Services to Very Young Children
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## PREFACE

This paper was researched and written by members of INTER-ACT: The National Committee for Services to Very Young Children with Special Needs and Their Families. INTER-ACT was founded in November 1978 by professionals with extensive experience in developing and directing model demonstration programs for very young children with special needs* and their families. The membership includes recognized leaders in the field and representatives of both public and private agencies, including university medical centers, public education agencies, community mental health centers, Easter Seal Societies and Cerebral Palsy Programs. All of these programs have received funding from federal agencies such as the Office of Special Education and Rehabilitation Services, Developmental Disabilities, Maternal and Child Health, and the Administration for Children, Youth and Families/Head Start.

At the May 1979 meeting of INTER-ACT, the members elected to prepare a position paper. The purposes for this paper were threefold:

1. to document the importance and efficacy of comprehensive early intervention services for children with special needs and their families;
2. to serve as a resource to a wide range of agencies, organizations and individuals concerned about the needs of very young children with special needs and their families (these include public agencies at the state, regional and local level; child and family advocacy organizations; parents and parent groups; professional organizations; legislators; and various professionals in fields related to the needs of children and families); and
3. to advocate support at all government levels for providing accessible, continuous, high quality services beginning at birth for children with special needs and their families.

The rationale for this position is that the earlier these children receive services, the greater potential there is for mitigating their disabilities and for enhancing their development and that of their families.

* The term "special needs" refers not only to children who have one or more identifiable handicaps, but also to children who are at risk of developing a handicap unless they receive special services during the first years of life.

## INTRODUCTION

In the past two decades, the federal government has enacted a number of federal laws specifically for the benefit of the handicapped. These include education laws under Title VI of the Elementary and Secondary Education Act, the Developmental Disabilities legislation, Section 504 of the Vocational Rehabilitation Act and, most recently, Public Law 94-142, the Education For All Handicapped Children Act. Federal agencies, such as the Office of Special Education and the newly formed National Institute for Handicapped Research, are presently providing funds and services to meet the needs of the handicapped. Other federal agencies, including the Administration for Children, Youth and Families/Project Head Start and the Maternal and Child Health/Crippled Children's Programs have directed a significant part of their efforts to providing services for the handicapped.

While the commitment to older handicapped children has grown, the commitment to the needs of handicapped children aged birth to three years and their families has remained disproportionately small. The National Foundation-March of Dimes reports that more than 250,000 infants are born each year with birth defects which may lead to physical handicaps, mental retardation, blindness, hearing loss or to other handicapping conditions (Facts '78, 1977). Another 50,000 infants are threatened with death or lifelong handicaps because they were born too soon or too small. Despite the evidence which documents the need for early intervention to the approximately one million handicapped children aged three and under and their families, there is no national mandate for providing services to this population.

Among states and communities, there is no consensus regarding the specific agencies which should assume responsibility for serving handicapped children aged birth to three and their families. As a result, there is an inevitable lack of coordination between planning and service delivery. This lack of coordination also exists at the federal level. For example, one agency is responsible for the identification of handicapped infants, another is responsible for the coordination of services, and none is mandated to provide comprehensive services beginning at birth to handicapped infants.

There is great need for a concerted effort at all government levels to ensure the availability of services for children aged birth to three with special needs and their families. An important part of that effort is the formulation of a national policy on the development of programs to provide these services. This paper is an attempt to document the need for early intervention in hopes that such a national policy will be considered and to recommend certain steps which advocates for young handicapped children should take in establishing service delivery systems to handicapped children aged birth to three and their families.

This paper is organized into four sections. Section one includes reviews of research which demonstrates the effectiveness of intervention programs and their impact on the development of very young handicapped children and on infants and toddlers at risk. Section two describes the effect of services on the family, identified family service needs and the rationale for the participation of families in programs for handicapped infants and toddlers. Section three shows data on the costs and cost-effectiveness of intervention programs for children aged birth to three, and the fourth section outlines the characteristics of a comprehensive service delivery system followed by specific recommendations for action at local, state and federal levels.

## SECTION I

## IMPACT ON CHILDREN

### Rationale for Service Provision

Through early intervention, handicapping conditions can be prevented or their deleterious impact on a child's development can be lessened. Intervention during infancy is especially important because of the rapid development which occurs in this period and because long term patterns of parent-child relationships are established at this time. Infant learning depends upon a match between the infant's capabilities and the stimulation provided by and responsiveness of the physical and social environment. The development of an infant with a handicap is constrained by his or her own limited ability to learn from experiences in a typical environment. Without intervention, the handicapped infant is unlikely to receive the benefits he or she needs from the environment.

### Background

The normal infant actively attends to and discriminates among stimuli with all of his or her senses. A wide variety of reflexive behaviors causes the infant involuntarily to perform many of the behaviors he or she will learn to control voluntarily by his or her first birthday. The infant demonstrates such adaptive reflexes as reacting to light with the pupils, turning when the cheek is touched and startling in response to loud noises. Grasping, creeping, walking, kicking and swimming reflexes evoked by specific sensations are among the reflex activities which bring the newborn into contact with the environment from which he or she begins learning at birth.

Beyond the newborn period, the normal infant shows progressive development in the motor, emotional, social, language and cognitive domains. Development in these domains is not discrete, and each area of development is difficult to separate from the other; thus a handicap in one domain may impinge on development in the other areas. The significance of these domains should become clear through the discussion of each below; of signal importance, however, is the interdependence of these domains in their effect on the total development of the child.

**Motor Development.** Motor development in the infant refers to an increasing ability both to achieve freedom from the primitive reflexes and impulses which govern early movement and to gain the control required for purposeful activity. In the first months of life, the infant primarily develops head control and grasping and kicking abilities. At the end of the first year, his or her motor development is marked by the ability to stand and walk alone and to hold and manipulate objects. Those skills are important because they encourage cognitive and social development by expanding the range of the infant's experience. The infant's new upright position and mobility facilitate interactions with other individuals. New language experiences and growth are possible for the infant as he or she perceives the world from an expanded view involving new people and things.

Many of the developmental milestones of infancy are in the motor domain, and motor dysfunction is often the first sign of developmental difficulties. Poor head control, inability to reach and grasp, and muscle tone either too loose or too rigid to support appropriate movement characterize the child with early motor problems. The crucial ability to get around

independently by creeping, crawling or walking may come late or not at all to the developmentally delayed infant.

Early intervention for handicapped infants who exhibit dysfunctions in the motor development domain is of primary importance. Since motor difficulties can be assessed early in life, intervention through developmental therapy should be provided as soon as this handicap becomes evident. For example, the cerebral palsied infant, perhaps unable to reach toward his or her mother, may not produce the necessary interaction cues so important for the mother-infant attachment process in the earliest months of life. This barrier to interaction can contribute to problems in later social and emotional development. Moreover, an infant who is physically unable to reach, grasp and thereby explore his or her environment may, consequently, be delayed in cognitive development. Poor control of the muscles of the lips, tongue and mouth can limit the infant's ability to produce meaningful speech sounds. Thus, the effect of a motor problem is also felt in the other developmental domains -- emotional/social and cognitive.

**Emotional and Social Development.** Socialization is the process by which the infant achieves competence in relationships with other people and learns to order his or her social environment. Attachment and initial socialization may well be the areas of development in which the infant's parents or caretakers have the most crucial influence. The ability to find comfort in a voice or touch, to recognize family members as different from the rest of the world and to respond to mother's familiar voice are early social skills. On these basic social skills of the infant lay the foundation for subsequent, increasingly organized capabilities, such as peer relationships, participation in sports, religious, legal and other community activities. From birth, then, the infant needs to interact with a parent or caregiver who is responsive to his or her cues and with whom he or she can achieve emotional reciprocity to form a secure attachment, for that attachment behavior is a template from which future social interactions take shape.

As the infant becomes increasingly independent, he or she begins to explore and form relationships with other individuals. Early emotional exchanges are expressed through touch, eye contact, smiling, gestures and language. These behaviors and other early social skills, such as crawling to an older sibling or waving "bye bye" to a grandparent, require visual, auditory and motor capabilities. Thus, visual, auditory or motor handicaps can impede an infant's emotional and social development, and the social skills of a handicapped infant or child frequently lag behind those of other children. Without intervention, for example, the blind child's interactions with his or her family and peers are often inappropriate and immature. Without the advantage of a shared communication system, it is difficult for the deaf or language-impaired child to relate to others. The physically handicapped infant or child, for example, is hampered in his or her efforts to approach and reach out to others. Early intervention provides either the means to share in the communication system of others, or an alternative system especially designed to compensate for the infant or child's particular handicap, thus ensuring him or her a fair, if not equal, chance to interact with others.

**Language Development.** While an infant may not seem to develop language skills until later, the first several months of life are a period of preparation for purposeful language use. Related skills such as locating the source of sounds, differentiating among sounds, and vocalizing (babbling and cooing) lay the basis for the further development of spoken language and for acquiring a grammatically coherent structure of interrelated symbols. The infant's early vocalization, while not language in a specific sense, serves to increase the control of vocal organs and to foster the infant's sense of self as a vocal, communicative creature.

The language foundations laid during the earliest months of life are frequently skewed for the infant handicapped in other areas of development. The wealth of literature on the deaf infant or child addresses the challenge facing parents, doctors and educators who must assist him or her with experiences leading to language development. Language also is integrally related to the visual environment. How does one explain "rainbow," for example, to a blind child? What does "yellow" mean? Other handicapping conditions create special language needs, such as those of the child whose cerebral palsy does not permit him or her to make clear speech sounds to express his or her thoughts and wishes. Creative approaches are required for communicating with and developing related skills in the young handicapped child during his or her early, critical years of language learning, approaches which involve time, training and professional assistance for both the child and the family.

**Cognitive Development.** In broadest terms, cognition is the process by which an individual translates experiences into abstract concepts or symbols which he or she can intellectually manipulate. Cognitive development for the infant involves learning to know himself or herself as separate from the environment, and then learning to understand the people and objects which inhabit that environment.

Jean Piaget has developed perhaps the most widely accepted theory of cognitive development to date. Piaget divides cognitive development into a number of stages, the first of which he calls the sensorimotor. The sensorimotor stage extends from birth to about the age of two years. During this period, the infant functions largely through reflex or acquired habit, and the patterns of behavior acquisition form the foundation of later formal symbolization. Toward the end of the sensorimotor period, the child uses symbolic cognition in simple problem-solving, at which time the child uses mental representation in directing his or her behavior. For example, if a child sees someone hide a stuffed animal under a blanket, he or she will search for the stuffed animal only as he or she learns to "remember" where the animal was hidden by retaining a mental representation of it. This term of symbolic function, called object permanence, is a prerequisite skill for more complex and abstract representation, such as language.

The child develops concepts initially through active trial and error. These trials gradually become internal and abstract. Often, the handicapped child encounters many "errors" in the process; often, he or she can initiate no trials. For example, the spinal bifida child, paralyzed from the waist down, cannot have the same experiences as the mobile infant. Crawling to the cabinets, pulling out the pots and pans and creating a lively household ruckus is not a spontaneous whim of independence for some handicapped infants. Such independence could only take place as a contrived, directed experience. Again, a physical impairment often impedes the learning process of the handicapped child, and the effects of the impairment are compensated for only through intervention.

Cognitive development, then, is not an isolated developmental domain, for it is integrally related with proficiency in motor skills and with social and emotional development. A child with a motor impairment may experience both social/emotional and cognitive delays as a consequence; similarly, a child with a cognitive impairment may experience a language deficiency likely to constrain his or her interaction with others. A cognitively delayed child could be deprived of the advantage of a fine discrimination of his or her parents. This deprivation would weaken the child's emotional attachment to the parents or caregiver, consequently restraining his or her social and environmental development. Through early intervention, infants and young children receive the services necessary to ameliorate the conditions obstructing their development in each of these domains. In the following subsection we will document the successes of early intervention programs with handicapped infants and children and their families.

**Effectiveness of Early Intervention Programs**

Through infant programs, interventionists have attempted to adapt environments, sequence experiences and educate parents in special techniques to help handicapped children compensate for their disabilities. As the following review of research indicates, researchers and educators have documented impressive successes in facilitating infant development through intervention programs which begin early in the lives of infants with wide ranges of handicapping conditions. Intervention programs have proved effective for infants with a variety of moderate and severe handicapping conditions, as demonstrated in each category of handicap below. While these categories do not reflect the standard classifications of handicapped children, they do show those classifications which have received major emphasis in the research.

**Mentally Retarded.** Researchers have been collecting data about the effectiveness of early intervention for several decades. As early as 1939, Skeels and Dye observed differential rates of development in mentally retarded children who benefited from environmental stimulation. They observed that the measured IQ of institutionalized retarded infants placed in the care of mildly retarded adolescent girls rose above that of infants who remained institutionalized and received no extra stimulation. A follow-up study conducted by Skeels (1966) years later showed that the significant gains in IQ scores of the infants persisted into adulthood. In contrast, the infants who remained institutionalized showed a loss in IQ scores over time. In a more recent study, follow-up of the University of Washington's Model Preschool graduates with various levels of mental retardation and language handicaps showed that these children required fewer special education placements at school age than similar children who did not have early intervention (Hayden, Morris, & Bailey, 1977).

**Down's Syndrome.** There is evidence that Down's syndrome infants in a parent/infant program at Boston Children's Hospital reached developmental milestones earlier than Down's syndrome infants who have not had early intervention (Zausmer, Pueschel, & Shea, 1972). Moreover, researchers at the University of Minnesota found that Down's syndrome infants who received early tutoring by their mothers exceeded controls in the areas of communication and cognitive skills (Moores, 1973). Similarly, results reported from a home-based program for Down's syndrome infants at the Center on Human Development at the University of Oregon showed that those infants' development can be accelerated "beyond the limits usually expected for these children" (Hanson, 1977, p. 5). Down's syndrome infants and preschoolers in a center-based program for handicapped children at the University of Washington's Model Preschool Center showed initial gains of 43% in motor and verbal responses (Hayden & Haring, 1976). Intervention in a setting with normal peers, which was provided to Down's syndrome infants and to infants with mental retardation from other causes, also has been proven effective (Bricker & Bricker, 1976). These successes are especially important because Down's syndrome is one of the most frequently identified causes of mental retardation, affecting one of every 640 babies born in America (Hayden & Haring, 1976). The beneficial effects of early intervention with Down's syndrome infants aged 3 to 37 months have also recently been demonstrated by Clunies-Ross (1979). Assessing those infants' progress on the Early Intervention Developmental Profile (EIDP), Clunies-Ross found not only that these children made significant gains but that the youngest children had the highest developmental gains over a period of 12 months. These findings support the premise that the earlier in a child's life intervention begins, the more benefits he or she will gain from that intervention.

**Neurologically Impaired.** Infants with other specific handicapping conditions also benefit from early provision of services. Neurologically impaired children aged 9 to 44 months made significant gains in the areas of physical, social and intellectual growth in an early intervention project at United Cerebral Palsy of Queens (Wider & Hicks, Note 1). Hochleiter (1977) reported a study in which 749 infants were examined during an eight year period. Infants with delays in neural development who were not treated in early life suffered moderate to severe motor impairment in 64% of the cases. However, when neurodevelopmental treatment was initiated early in life, 87% of the children were reported to have achieved a normal life style.

**Sensory Impaired.** Several studies demonstrated the effectiveness of early intervention with infants who had sensory handicaps, such as hearing or vision problems. In a program for severely hearing-impaired children at the Bill Wilkerson Center in Nashville, there were significant differences on measures of language complexity and achievement tests between children who had entered the program before the age of three and those who entered after the age of three. Those children who received earlier intervention and stimulation were similar to normal hearing children on both the language and achievement measures (Horton, 1976). Furthermore, Northcott (1971) reported that early intervention among the deaf prevented the development of maladaptive behaviors which contributes to poor integration of deaf children into society.

A longitudinal study of the gross motor development of ten blind infants was performed at the Child Development Project at the University of Michigan Medical Center. Results of the study indicated that the children who received intervention services in comparison to those who did not were within the developmental age ranges for sighted infants on the Bayley Scales of Infant Development in the areas of neuromuscular maturation and postural achievement. Delays in self-initiated locomotion and mobility were related to the blind infants' "normally" late adaptive substitution of sound for sight as incentive for mobility (Adelson & Fraiberg, 1975).

**Severely/Profoundly Handicapped.** In the case of severely/profoundly handicapped infants, Scheifelbusch (1978) reported that early intervention increases the probability of ameliorating the long term effects of developmental disorders, thereby possibly preventing eventual deformity and suffering. In a more recent study of 50 severely/profoundly handicapped children aged birth to five enrolled in the University of Miami's Mailman Center, Bricker and Dow (1980) reported significant gains in the Uniform Performance Assessment System (UPAS) scores for those children who received intervention. Furthermore, the UPAS scores were found to be significant predictors of subsequent scores and subsequent school placement. Eighty-eight percent of the children were placed in public school programs, four percent in group homes, two percent in public school programs, and six percent in other programs. Overall these findings further corroborate the Scheifelbusch study and show significant positive effects of early intervention on severely/profoundly and handicapped infants and children. In addition, multihandicapped infants at the University of Virginia's Education for Multihandicapped Infants program entered with delayed developmental rates and showed significant gains in developmental rates after two years of parent/infant education and therapy. These children demonstrated that they had continued to learn at improved rates when retested at ages three and five (Elder, 1976).

**Intervention With Newborns**

For more than a decade, researchers have investigated the effectiveness of specific treatment to prevent the potentially harmful handicapping effects of the neonatal environment of the infant at risk who must spend his or her early weeks in a hospital intensive care nursery. There has been a theoretical difference among researchers as to the specific factors in the environment of intensive care nurseries which contribute to subsequent developmental delay in the infant. Some have planned interventions from the hypothesis that infants in intensive care are deprived of the stimulation usually gained from interactions with the family in a home environment (Cornell & Gottfried, 1976). Others have approached intervention as compensation for the overstimulation of around-the-clock bright lights and bustling nurses (Lawson, Daum, & Turkewitz, 1977).

One of the earliest studies of the intensive care nursery was performed by Hasselmeyer (1966). She believed that the then current "minimal handling" treatment approach was inconsistent with theories of normal infant development and found that premature infants in the nursery who received extra handling by nurses (stroking, rocking, cuddling) cried less and were quieter than premature infants in a control group. Moreover, in a study by Solkoff, Kaffe, Weintraub, and Blase (1969), premature infants who received ten days of extra stroking from their nurses cried less, gained weight faster and were more active than controls. At eight months of age, Bayley Motor Scale scores were higher for the treated infants than for the control group. Similarly, Freedman and Boverman (1966), using an inanimate rocking device in isolettes, found temporary weight gain and marked increase in relaxation in premature infants rocked for one hour daily. Neal (1968) provided premature infants with mechanical vestibular stimulation for 1½ hours daily and found these infants surpassed controls on Graham/Rosenblith measures of visual, auditory and motor responses.

Auditory, rather than tactile/kinesthetic, stimulation was provided to premature infants in a study by Katz (1971). Infants in their isolettes heard tape recordings of their mothers' voices for a total of one-half hour daily. These infants performed significantly better than controls on Graham/Rosenblith tests of motor, tactile-adaptive, visual and auditory behavior. Barnard (1972) provided premature infants with both auditory stimulation (recorded heart beat) and kinesthetic stimulation (mechanical rocker in the isolette) for one quarter of each hour daily. These infants tended to show greater weight gain and maturity scores than controls on the Dubowitz scale which measures physical and neuromuscular maturity. They also showed a significant increase in the total amount and periodic lengths of time spent in the quiet sleep state, a sign which has been associated with more mature cortical functioning. One year later, the same infants surpassed controls on motor and mental assessment measures.

Adding another dimension to these studies, Scarr-Salapatek and Williams (1973) provided inanimate visual stimulation (mobiles) and animate auditory and tactile/kinesthetic stimulation (four hours daily of rocking, patting, talking en face) for low birth weight infants during the nursery stay. They also provided weekly home visits and parent education during the infants' first year of life. The low birth weight infants in this study performed better than controls on the Brazelton Neonatal Scales at one month of age and on the Cattell Infant Intelligence Scale at one year of age.

Nurses gave low birth weight infants extra handling for forty minutes daily in Powell's study (1974) and encouraged maternal visiting and handling. The infants tended to gain weight faster than controls, although not significantly so. Follow-up testing at four months showed, however, that the handled infants surpassed controls on the Bayley Mental and Motor Scales. In a study by Solkoff and Matuszak (1975), low birth weight infants who received a total of two hours daily tactile stimulation (stroking) for ten days during their nursery stay demonstrated superior Brazelton Scale scores when compared with control infants.

Premature infants who received an extra hour of daily tactile, kinesthetic, vestibular and auditory stimulation during their nursery stay were tested at six months of age by Rose and Bridger (Note 2). These infants were found to surpass control infants and to perform as well as full-term infants of the same age on measures of visual recognition memory, which has been found to correlate with intelligence scores at four and six years of age (Fagan, Note 3).

These important elements of effective intervention identified in studies with premature and newborn infants have been summarized by Barnard (1976). They include: 1) inanimate auditory and vestibular stimulation, 2) inanimate visual stimulation, 3) animate tactile/kinesthetic stimulation through handling, 4) animate visual and auditory stimulation through language, and 5) parent support and education. Intervention with infants during the newborn stage includes both relaxation (stroking, rocking and cuddling) and stimulation (auditory, visual, tactile and vestibular) as well as parent education. Understimulation and overstimulation, therefore, may be a focus for intervention, but, most importantly, intervention in whatever form taken results in a significant advantage to those infants who receive it.

The research conducted so far with premature and at-risk infants indicates that intervention beginning in the intensive care nursery greatly improves the chances for these infants to reach normal or near normal levels of development at an early age. Intervention with at-risk and normal infants results in greater gains in areas such as cognition, behavior, weight gain, motor development and visual and auditory functioning. Based on a review of studies, Lipsitt (1979) stated, "While it would be foolhardy to suppose that special regiments of stimulation and of learning experiences can compensate for all constitutional insufficiencies in the young child, there is increasing evidence to indicate that the high-risk infant may indeed benefit from special environmental manipulations" (p. 155). In view of this research, we conclude with Masi (1979) that despite some methodological problems inherent in the research "the provision of appropriate sensory stimulation is an important component of quality care for premature infants" (p. 380). We also understand, nevertheless, that intervention cannot stop with infants alone receiving services; intervention must extend to older infants and children as well.

**Summary**

Infants with special needs are not always identified during the newborn period, and in some cases, the special needs may be transient. Evidence does exist that intervention with older infants and toddlers who have identified needs and who have previously received intervention services may benefit from these services. Researchers and interventionists have collected further evidence, some of which we have reviewed above, which corroborate the conclusion that intervention beginning in the first two years -- the years of rapid growth and development -- is more effective than that beginning later in the child's life. Moreover, as we will point out in a later section, these services, though initially expensive, decrease the cost of special services to the children over time. For example, children between birth and three years of age in the Delayed Development Project in Stockton, California, exceeded controls in two out of four of the Denver Developmental Screening Test areas during the two years in which control groups were available (Stockton Unified School District, 1973). In addition, the Portage Project in Wisconsin, a home-based intervention program for delayed children from birth to six years, reported that children with initial IQs of 75, who should be expected to achieve gains of six months in an eight-month period, made developmental gains of thirteen months in eight months' time (Shearer & Shearer, 1972). Lazar (1979), compiling data from fourteen longitudinal studies of low-income children who were served under infant and preschool developmental programs prior to 1969, reports that the children: 1) required special education less frequently, 2) were retained in a grade less often, and 3) scored consistently

higher on intelligence tests. Lazar also reported favorable reactions from parents regarding perceived program benefits.

Synthesis of data from 32 infant and toddler intervention programs in the Handicapped Children's Early Education Programs network showed the effectiveness of these programs in improving children's development, specifically in the area of personal-social behavior (Stock, Newborg, Wnek, Schenck, Gabel, Spurgeon, & Ray, 1976). Furthermore, two-thirds of the children who had benefited from these programs were able to move into regular classrooms at school age. Their teachers reported that the social and cognitive skills of these handicapped children surpassed those of similarly handicapped children deprived of early intervention. A more recent study of handicapped infants in six intervention programs in the Texas Consortium (Macy Research Associates, 1978) showed that participating children had made significant improvements in developmental skills from the time they entered until the time they left the program.

In another review of reports from a number of early intervention programs for mildly retarded children, Ramey, Stedman, Borders-Patterson, and Mengal (1978) concluded that "early education intervention during the preschool years can result in superior intellectual performance for mildy retarded children who have received systematic educational programs, when compared with those who have not" (p. 525).

As we have suggested, some aspects of this intervention involve working with the parents as well as with the infants or children. In 1972, the Secretary of Health, Education and Welfare funded a survey of results from forty longitudinal intervention programs with high-risk infants. The following major conclusions (Stedman, 1977) summarize the importance of early intervention and of home-based services which treat both the family and the child, the topic of our next section:

- The effects of a stimulating or depriving environment appear to be most powerful in the early years of childhood when the most rapid growth and development take place. The primary focus of the child during these years is the home. Therefore, home-based intervention programs or one-to-one teacher-child ratio stimulation activities appear to be the most appropriate and effective during this period.

- There is evidence that the effects of early intervention programs for children are strengthened by the involvement of the child's parents.

- In situations where families are so disorganized that they cannot supply a supportive environment, an intensive external supportive environment may contribute to the child's development.

- Where access to children can be gained in the early years, preferably during the language emergent years (one to two years of age), intervention programs are more effective than those begun at later ages.

- The quality and motivation of the staff are directly related to the success of the program and, therefore, are prime factors in determining the extent to which a program is exportable or replicable. (pp. 2-3)

Many studies have shown that early intervention efforts with handicapped infants and children have been effective in accelerating and maintaining their development. As Hayden and McGinness (1977) have said, "Early intervention has been shown to help: it can work to reduce the effects of a handicapping condition, and can do so more surely and more rapidly

than later intervention" (p. 160). Recent evidence indicates that this statement should be read quite literally, for improved intervention techniques with newborn and premature infants are showing significant positive impact on the developmental prognosis of at-risk and handicapped infants.

In the next section, we shall examine more closely the benefits of comprehensive services to at-risk and handicapped infants and children, services which reach into the children's homes -- ideally their most supportive environment -- or which, at the minimum, involve the children's parents and siblings.

## SECTION II

## IMPACT ON THE FAMILY

### History of Parent Involvement

Involving parents as a means of influencing child development has been a mandated feature of early education programs since 1966 when Head Start was created. Subsequent legislation creating the Handicapped Children's Early Education Program (HCEEP) expanded parent roles in federally supported programs. Parents now participate in program planning and operation, policy formulation, program and child progress evaluation, as well as in program dissemination activities.

The Education for All Handicapped Children Act (P. L. 94-142) provided for parent participation in the writing, approval and evaluation of each handicapped child's individualized education plan (IEP). Parents' participation in making decisions about and becoming actively involved in their child's education is now a guaranteed legal right. Thus, federal precedents for involvement have been established for parents of handicapped children and for parents of economically disadvantaged children.

The importance of involving parents in early education programs has been substantiated by significant research (Bronfenbrenner, 1975b; Goodson & Hess, 1975; Gordon, 1975; Karnes, Studley, Wright, & Hodgins, 1968; Karnes & Zehrback, 1975; Weikart, Deloria, Lawsen, & Wiegernik, 1970; ). Intervention which does not include the caregiver is usually less effective, while intervention which focuses on the parent is usually more effective (Bronfenbrenner, 1975; Parmalee, in press). Moreover, parent involvement in intervention programs has partially alleviated the personnel shortages faced by some programs (Clements & Alexander, 1975; Ora, 1973; Reisinger, Ora, & Franzia, 1970) and has resulted in cost-saving benefits (Macy Research Associates, 1978).

### Impact of the Child on the Parent

Each participant in an interaction influences subsequent responses from the other(s). The infant's characteristics and functioning influence a parent's response in many ways (Minde, Morton, Manning, & Hines, 1980; Parmalee, in press). Moreover, the well-being of an infant is a source of maternal self-esteem (Duchowny, Note 4); eye-to-eye contact between mother and child seems to foster positive maternal feelings (Robson, 1967); maternal behavior varies as a function of the state or activity level of the infant (Levy, 1958). Not only do mothers benefit from these earliest parent-child interactions, but fathers do as well. Greenberg and Morris (Note 5) have shown that the impact of a healthy newborn on the father ranges from attraction to the infant to an increased sense of self-esteem.

All children require interactions with their parents or caregivers to meet their developmental needs and to form secure attachments, but the behavior of the child with special needs makes it difficult for his or her parents to respond in such a way as to provide appropriate developmental support. Kelly (1980) states: "Infant specialists recognize that the presence of a handicapping condition in infancy can complicate parent-infant interaction and jeopardize the successful functioning of the family unit" (p. 7).

Based on her recent literature review on the effects of a handicapped child on the family unit, Kelly (1980) concluded the following:

a. Parents of handicapped children have unique needs in integrating the child into the family unit.

b. Parent-infant interaction is crucial to infant development, and that interaction can be complicated by the birth of a child who is handicapped.

c. It is important for parents to understand their child's health and developmental status and to be able to provide an environment that fosters social and emotional growth (pp. 14-15).

Prechtl's (1963) observations of minimally brain-impaired children suggest that hyperactive and hypertonic children have difficulty orienting themselves in a relaxed way to their mother's physical contact. It was found that these children had difficulty holding themselves in a cuddling position, thus hindering positive interaction, attachment and perceptions by the parent of the child's needs. Stone and Chesney (1978) found that handicapped infant and toddler attachment behaviors were delayed or diminished in strength. The young child with special needs, then, presents a unique problem concerning parent-child attachments.

Campbell (Note 6) found that mothers who perceived their infants as difficult to handle interacted with their infants less and were less responsive to their social cues. Another outcome which has been reported (Klein & Stern, 1971) is that handicapped children are more likely to be abused than are nonhandicapped children. Nevertheless, when parents are able to understand a handicapped infant's needs, they become more responsive and thus support the infant's development (Fraiberg, 1971). Of central importance is the responsiveness of the mother to the infant's signals and her ability to respond appropriately and sensitively. Stone (1979) reported a number of variations in maternal attachment behaviors which must develop as a response to handicapping conditions in infants.

The critical point is that the parent, according to Campbell (Note 6) must learn to recognize the infant's signals in order to use appropriate stimulation behaviors and routines in interactional patterns. Such parental sensitivity creates an environment conducive to cognitive and emotional development. Clarke-Stewart (1973) found that stimulating responsive maternal behaviors influenced the child's intellectual development, while in the area of social relations, the child's behavior influenced the mother. In summary, Als, Tronick, and Brazelton (Note 7) point out that parents and infants have a mutual communication system which reciprocally meets their biological and psychological needs. It follows that this system is as essential for the child with special needs and his or her family as it is for the nonhandicapped child.

**Involvement of the Father**

Traditionally, the mother-infant relationship has been seen as the principal support for the development of the child. The impact of the father on the child, however, is changing as involvement by fathers in child-rearing increases. Concurrently, researchers have focused more attention on the father's impact on the development of infants.

The quality of the father-infant interaction has been shown to affect the infant's cognitive development (Clarke-Stewart, 1978). The father, like the mother, has both direct and indirect influence on various aspects of infant development. Biller and Meredith (1974) and Lynn (1974) stressed the quality of the father-child relationship as an important variable in the child's development. Their research demonstrates the significance of the establishment of a warm father-child relationship in early infancy in order to foster adaptive development. Further corroboration of these studies comes from Pedersen (Note 8) who found that when the father of a high-risk infant supported the mother, the mother demonstrated greater feeding competence. If the marital relationship was fraught with high tension and conflict, though,

the mother demonstrated inept feeding. In both cases, the status and well-being of the infant was found to be related to the marital relationship.

When we consider that fathers of handicapped children generally experience more marital dissatisfaction and loss of self esteem, we see the extent of the problem and the need for intervention. Cummings (1976), for example, found that fathers of handicapped children were less assertive and demonstrated a greater need for order than fathers of normal children. In addition, these fathers were reported to experience decreased satisfaction in their marital relationship and to display less self-esteem, in contrast to fathers of normal children. Fortunately, it has been shown that intervention is effective in mitigating at least some of these problems by improving the fathers' responses to their handicapped children.

In his recent review of literature on father-infant interaction, Delaney (1979) asserted:

> Theories have been postulated which suggest that increasing a father's awareness of child development facilitates the establishment of normal attachment between father and infant when the infant is handicapped. (p. i)

In order to test this hypothesis, he provided an intervention program for fathers of handicapped infants consisting of activities designed to promote the fathers' awareness of infant development. Delaney found that attachment between fathers and their handicapped infants may be facilitated by increasing the fathers' awareness of child development and by increasing the fathers' ability to respond to his child's individual needs.

**Family Involvement in Intervention Programs**

The recommendation for the involvement of families in programs for their handicapped children is based on the belief that parents are the child's primary teachers and that they provide the most effective, as well as the most economical, means for fostering child growth and development. Research which has identified the parent/caregiver as the primary agent in influencing the young child's development and especially the young handicapped child's development (Bronfenbrenner, 1975; Karnes, Studley, Wright & Hodgins, 1968; Karnes & Zehrback, 1975) supports this belief.

Because the infant is a member of the family system, family involvement and impact become a major consideration in many intervention programs. Bromwich (1977) reviewed considerable medical and psychological research and concluded that improving parenting knowledge and skills was more beneficial than just focusing on infant stimulations. Bromwich spoke in terms of "parent-infant" education and argued for: 1) increased parent awareness of the infant's sensory tolerance and temperamental organization, 2) increased enjoyment of the infant and responsiveness to his or her communications, and 3) increased ability to anticipate developmental changes in the infant's behavior. Longitudinal studies reported by Elardo, Bradley, and Caldwell (1975, 1977) support these recommendations about parent involvement in early intervention. Results typically showed that parents' provision of warm and supportive environments which encouraged exploration and independence led to more rapid language development and higher IQ scores in infants by the age of three years.

Brazelton (1979) reported that services to parents in intervention programs could help parents convert their feelings of grief over the birth of a handicapped child into a desire to develop parenting skills to enhance their child's development. In those families in which parents shared similar positive attitudes toward their handicapped child, the other children in the family showed less disturbance and were better able to adapt and to cope. In a related study by Field, Widmayer, Stringer, and Ignatoff (1979), teenage mothers who participated in a parent education intervention program manifested more optimal interactive behavior and their

children were found to be more advanced on the Denver Developmental Screening Test than children in a control group who were not in the program. Badger (1974) found that parent education programs for low socioeconomic status teenage mothers enhanced both the parents' behavior and the children's development.

A significant finding is that parents may offset or reduce traumas in the infant associated with prenatal stress, such as anoxia and low birth weight, through practices which facilitate development. However, noncontingent caretaking can amplify the effects of intrinsic pathology (Drillien, 1972; Harper & Weiner, 1965; Parmalee, in press; Werner, Bierman, & French, 1971). Parmalee provides evidence that the significance of medical complications in the infant depends to some extent on the caregiver's mediating reponses and concludes that intervention directed at parent-infant interaction is the most productive approach for intervening with these high-risk infants. The effect of intervention, therefore, has the potential of enhancing the functioning of the entire family unit.

Although program outcomes generally are measured in the area of developmental gains made by the handicapped infant, some studies have reported aspects of the effect of the program on the family. For example, parents in intervention programs have reported increased emotional support (Lillie, 1975), satisfaction, self-esteem, competence, and a positive impact on their friendships and outside activities (Hess, Block, Costello, Knowles, & Largary, 1971). In those families where parents shared similar and positive attitudes toward the handicapped child, the other siblings showed less disturbance in the home, at school and in social activities. The siblings that were able to adapt and cope best came from homes where parents spoke openly about the handicapped child, included the sibling in decisions, and elicited their help in integrating the child into the community (Grossman, 1972; Lavine, 1977). Parents of well-adjusted siblings reported that they taught their children how to deal with feelings of hostility and aggression towards the handicapped child, and what were the unique problems and etiology of the child's handicapping condition (Grossman, 1972; Lavine, 1977). This finding supports an earlier study of programs which provided group experiences for siblings. These siblings stated that as a result of their group participation, they felt better about themselves and were able to interact more appropriately with their handicapped siblings (Schreiber & Feeley, 1965).

The research shows, then, that services for at-risk or handicapped infants and toddlers, while necessary and effective, are not entirely sufficient. The parents of these infants must also receive services which afford them the knowledge, understanding and attitudes to exercise proficiently their responsibilities as the primary decision makers, care-givers, teachers and advocates for their own children. It is only through these comprehensive services that handicapped infants or children and their families will overcome or compensate for the constraints arising from the particular at-risk or handicapping conditions they face. Moreover, as we will now point out, these initial comprehensive services are cost-effective, because they will reduce the need for or the extent of intensive and expensive, long-term services in later years.

## SECTION III

## COSTS OF INTERVENTION PROGRAMS

Is early intervention for handicapped or at-risk children cost effective? There are numerous methodological problems which make this question difficult to answer. For example, the cost per child may vary by year because of increasing age, because of changes in the handicapping condition, or because educational or maturational effects warrant new educational programs. Another problem in determining cost effectiveness of early intervention programs is the lack of compatible record-keeping systems and cost data from program to program. Finally there is the problem of variable costs for both handicapped and nonhandicapped education across the country.

While we could project many scenarios about a handicapped child's entry point into special education and exit point into regular education, there are insufficient data about what actually occurs as a result of beginning special education intervention at birth (infant program), at age two (preschool), at age six (elementary school) or at age twelve (middle/high school). In view of these problems, determining cost effectiveness of early intervention programs for handicapped and at-risk infants and young children at the present time depends upon piecing together data from several sources. In this section, we have collected various cost data in order to estimate the average costs and cost savings of early intervention.

Before explaining in detail the computations and their justification, we will present an overview of the cost model. The model presented here is based on the idea that intervention results in proportional attrition rates from special education into regular education from one educational level to another. The model derives from graduation data collected from several studies (Macy & Carter, 1980; Macy Research Associates, 1978; Stock, et al., 1976; DeWeerd, Note 11) and assumes that those going into regular education will remain there. The percentage of children who leave special education and go into regular education are, at each level: 12%, from birth to two; 55.8%, from two to six years; and 33%, from six to 18 years of age (Figure 1). The median costs of special education per child per year are $2,021 for infants, $2,310 for preschoolers and $4,445 for elementary and secondary students (Figures 1 and 2). Thus, the costs of special education and services for handicapped infants and children not only increase at each higher level, but the numbers of infants and children requiring services increase at each level as intervention is postponed, for as intervention is postponed in a population, the individuals in that population have lower rates of entering regular education programs. Figure 1 demonstrates the rising costs and rising numbers needing services, assuming a population of 940 children receiving services at birth, at two years, and at six years of age. Delaying intervention means more children requiring more services at higher costs; early intervention for the same population means fewer children requiring high cost services.

### Estimating Cost Effectiveness of Early Intervention

In considering the cost of early intervention for handicapped or at-risk chidren and their parents, it is important to recognize that the cost of special services for handicapped students is typically greater than the cost for nonhandicapped students (Figure 3). However, when comparing alternative options for the age at which special intervention should begin, the analysis presented in this section indicates that early intervention is cost effective. There were substantial savings when intervention began at age two and maximum savings when the program was initiated during the first two years of life. Compared with beginning intervention

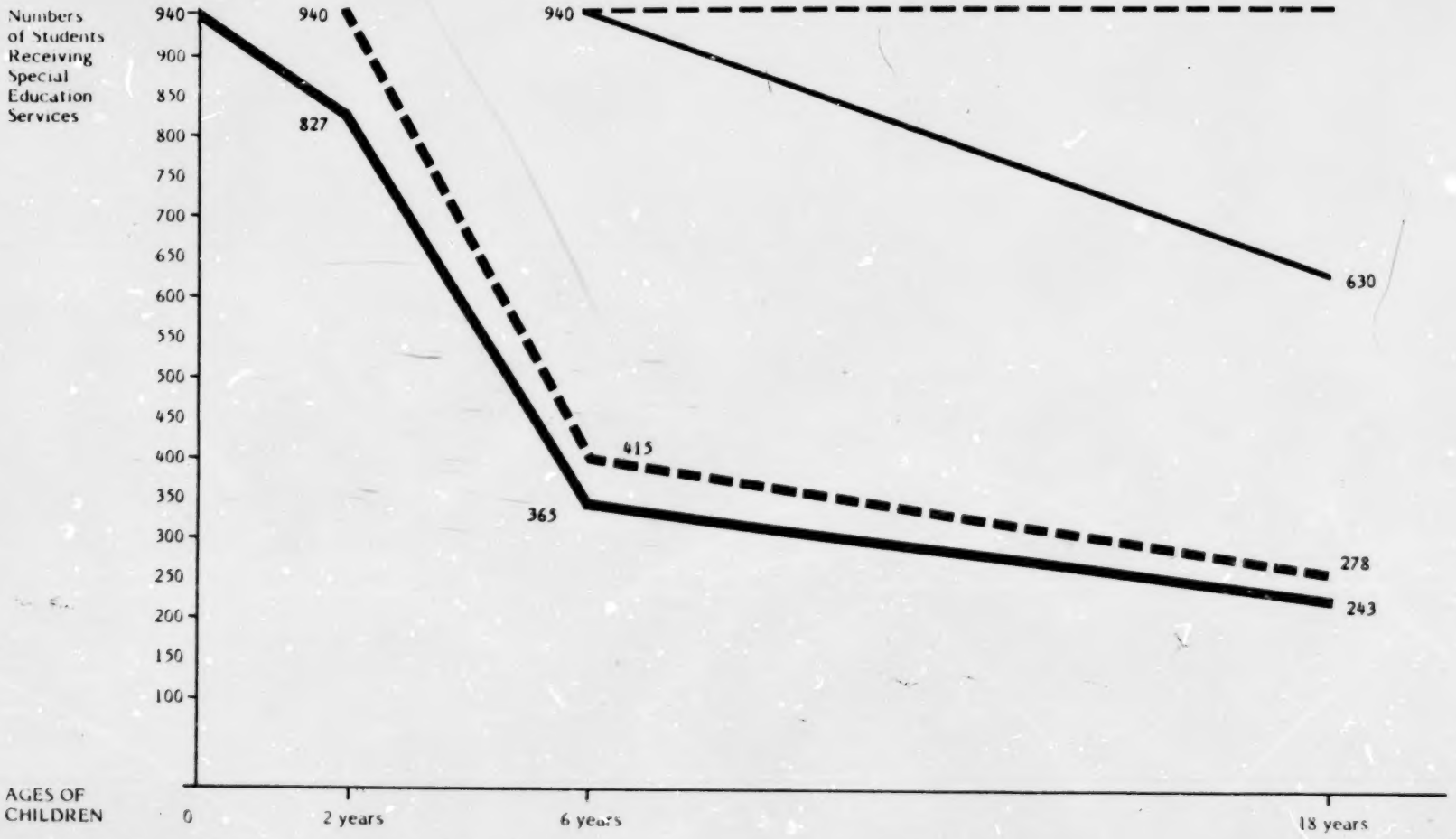


**Figure 1**

**Comparison of Costs of Special Education As Intervention is Delayed**

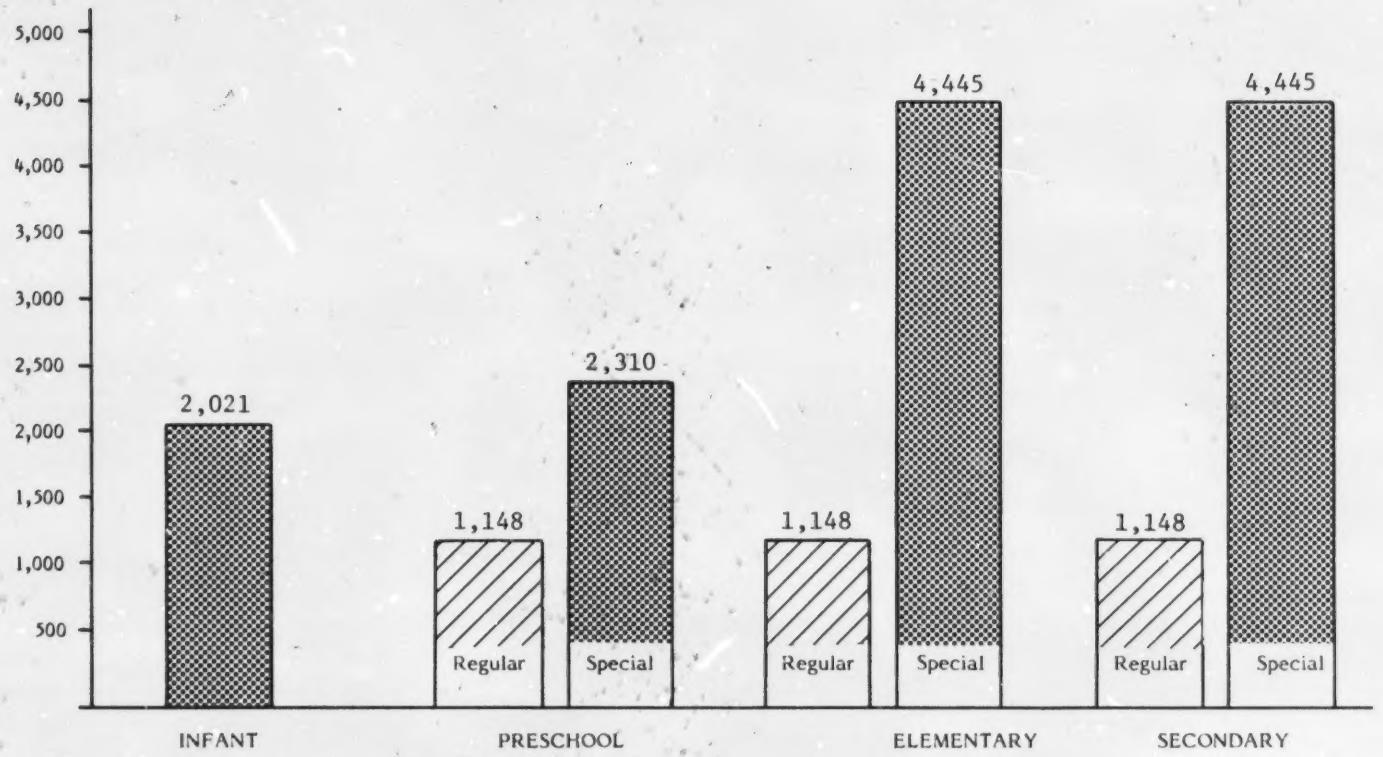


**Figure 2**

**Median Cost of Special Education**

**Per Child Per Year**

(12 Months)

(1978-79 figures)

Regular Education

Special Education

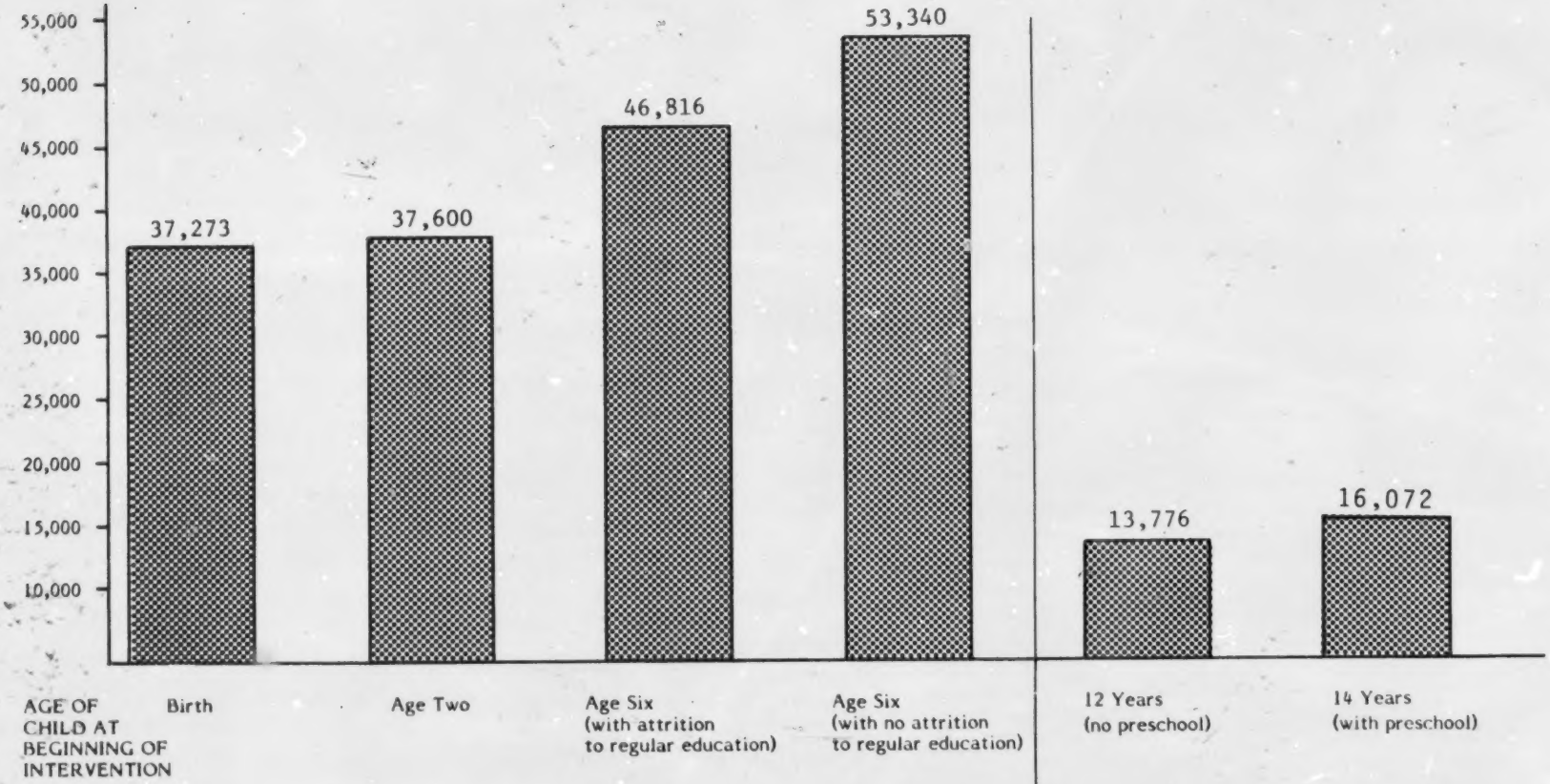


**Figure 3**

**Total Special Education Costs Per Child to Age 18**

(Adjusted to 1978-79 levels)

(Based on study of 940 multiply handicapped children, ranging from severely to mildly mentally retarded)

at age six, these preschool programs resulted in a savings from $9,000 to $10,000 per child for the cost of education to age 18.

We used four alternative plans to calculate the relative costs of educating a group of 940 young handicapped children to age 18. The results of these calculations indicate clear savings when a program is initiated at birth and maximum savings when intervention begins at age two. The total educational costs per child receiving intervention to age 18 with intervention beginning at each level are: $37,273, intervention beginning at birth; $37,600, at age two years; $46,816, at age six years; and $53,340, at age six years with no attrition to regular education (Figure 3). In order to calculate these costs, numerous assumptions had to be made because the data were obtained from several sources and pooled to make typical estimates. Table 1 contains the calculations, adjusted to 1978-79 levels[1]. The following sections describe the data sources, procedures, assumptions and limitations used to arrive at these figures.

**Infant and Preschool Special Program Costs.** A median cost for 1978-79 of $2,021 per infant per year (12 months) was obtained by using the actual median cost of $2,272 reported for services to infants, birth to two years, in the Texas Consortium in 1979-80 adjusted for inflation to 1978-79 levels (Macy and Carter, 1980, Table 30).[2] This cost figure represents a median, 12-month cost for 16 infant programs serving 1,613 handicapped children under age two. A median cost for 1978-79 of $2,310 per child per year (12 months) for preschool special programs was computed from the reported actual cost of $1,995 in 1977-78 for similar programs in the National Diffusion Network (NDN) from seven states (Far West Laboratory for Educational Research and Development, 1979).[3] In contrast to the cost figure reported by the Texas Consortium specifically for programs serving children from birth to two years, the higher NDN cost figure appears to be representative of programs which serve handicapped youngsters between the ages of two and five years (Stock, et al., 1976).

There are several factors which may contribute to these cost differences between the infant programs and the preschool programs. Information from the Texas Consortium suggests that infants to age two typically receive only 1.33 hours of service per day (Macy and Carter, 1980). While no information was available about actual contact hours for children in the NDN programs, these programs typically offer more hours of service per day, thus increasing personnel costs. Another factor may be differences in the amount of contributed (volunteer) service. The Texas Consortium reported 16,919 hours of direct instruction contributed by parents. This contribution of time represents $44,835, using a minimum wage value, or $131,122, using a professional wage value (Macy Research Associates, 1978).

Several other points need to be made about these costs. First, in contrast to school-age program costs which typically are reported on a 10-month basis, a 12-month program is generally considered necessary for the very young handicapped, because critical aspects of development occur year round and the severity of the handicapping condition requires

---

[1]1978-79 was arbitrarily selected because cost data have been drawn from various cost reports between 1977 and 1980. All costs were adjusted for inflation upward or downward accordingly.

[2]To reduce the 1979-80 figure to 1978-79 equivalent, a 12.4% inflation rate was used.

[3]Macy and Carter (1980, Table 30) report a median NDN cost per child of $2,597 in 1980 (adjusted for inflation). To obtain the 1978-79 median cost, this figure was reduced by 12.4% for inflation.

Table 1

Comparison of Costs of Educating 940 Handicapped Youngsters to Age 18 Beginning at Different Intervention Points

| Program Annual Per Pupil Costs* | INFANT Special @ $2,021 per year N (%) Years | Cost Subtotal | PRESCHOOL Regular @ $1,148 per year N (%) Years | Special @ $2,310 per year N (%) Years | Cost Subtotal |
|---|---|---|---|---|---|
| OPTION #1: | 940 (100) X 1- | (1,899,740) | 113 (12) X 4 - | ----- | (518,896) |
| | | | | 827 (88) X 4 - | (7,641,480) |
| Intervention Begins At Birth | | (1,899,740) | | | (8,160,376) |
| OPTION #2: | | | | 940 (100) X 4 - | (8,685,600) |
| Intervention Begins At Age 2 | | | | | (8,685,600) |
| OPTION #3: | | | | | |
| Intervention Begins At Age 6 | | | | | |
| OPTION #4: | | | | | |
| Intervention Begins At Age 8 (with no attrition to regular education) | | | | | |

*Cost estimates are based on 1978-79 figures.

**Table 1** (Cont'd)

**Comparison of Costs of Educating 940 Handicapped Youngsters to Age 18 Beginning at Different Intervention Points**

| Program Annual Per Pupil Costs* | SECONDARY<br>Regular @ $1,148 per year<br>N (%) Years | Special @ $4,445 per year<br>N (%) Years | Cost Subtotal | Cost Per Pupil to Age 18 |
|---|---|---|---|---|
| OPTION #1:<br>Intervention Begins At Birth | 113 -- X 6 -<br>462 -- X 6 -<br>122 (33) X 6 - | ----<br>----<br>----<br>243 (67) X 6 - | (778,344)<br>(3,182,256)<br>(840,336)<br>(6,480,810)<br>(11,281,746) | |
| | TOTAL OPTION #1 | - | $35,037,012 | $37,273 |
| OPTION #2:<br>Intervention Begins At Age 2 | 525 -- X 6 -<br>137 (33) X 6 - | ----<br>----<br>278 (67) X 6 - | (3,616,200)<br>(943,656)<br>(7,414,260)<br>(11,974,116) | |
| | TOTAL OPTION #2 | - | $35,343,966 | $37,600 |
| OPTION #3:<br>Intervention Begins At Age 6 | 310 (33) X 6 - | ----<br>630 (67) X 6 - | (2,135,280)<br>(16,802,100)<br>(18,937,380) | |
| | TOTAL OPTION #3 | - | $44,007,180 | $46,016 |
| OPTION #4:<br>Intervention Begins At Age 8 (with no attrition to regular education) | ---- | 940 (100) X 6 - | (25,069,800) | |
| | TOTAL OPTION #4 | - | $50,139,600 | $53,340 |

Table 2

Computations for Determining Annual Cost for Special Elementary and Secondary Programs (N=940 Handicapped Children)

| (1) Area of Handicap | (2) Cost Factor* (Florida) | (3) % of Children in Each Category (Texas Consortium) | (4) 80% of Col. 3 (Adj. for Multi-Handi.) | (5) Annual 1.0 Cost Factor* (Florida) | (6) No. Children in Each Category (940 x Col. 4) | (7) Cost Per Child in Category in Col. 1 (Col. 2 x Col. 5) | (8) Total Cost for Group of 940 (Col. 6 x Col. 7 |
|---|---|---|---|---|---|---|---|
| TMR | 2.75 | 26.0 | 21 | $1,148 | 198 | $3,157 | $625,086 |
| EMR (DD) | 2.07 | 22.1 | 18 | 1,148 | 169 | 2,367 | 401,544 |
| ORTHOPEDIC | 7.10 | 14.3 | 11 | 1,148 | 103 | 8,151 | 839,553 |
| OHI | 3.56 | 17.1 | 14 | 1,148 | 132 | 4,087 | 539,484 |
| SPEECH/ LANGUAGE | 6.83 | 9.7 | 8 | 1,148 | 75 | 7,841 | 588,075 |
| DEAF/ AUDITORY | 3.67 | 3.9 | 3 | 1,148 | 28 | 4,213 | 117,964 |
| BLIND/ VISION | 3.53 | 3.9 | 3 | 1,148 | 28 | 4,052 | 113,456 |
| ED | 2.95 | 3.0 | 2 | 1,148 | 19 | 3,387 | 64,353 |
| SEVERELY MULTI-H.C. | 4.12 | --- | 20 | 1,148 | 188 | 4,730 | 889,240 |
| TOTAL | --- | 100% | 100% | --- | 940 | | ($4,178,755) |
| AVERAGE COST PER CHILD PER YEAR (TOTAL ÷ 940) | | | | | | | $4,445 |

*Based on actual 1978-79 costs.

sustained intervention to combat the potentially deleterious effect of the handicap on otherwise normal development. Second, the NDN cost figure probably does not include capital costs (land, buildings, vehicles, etc.) which often are included in cost figures for school-age programs. Early intervention programs usually do not have major capital expenditures, while per child school-age costs typically contain prorated capital expenditures.

**School-Age Special Program Costs.** An annual cost of $4,445 was calculated for special education for these 940 handicapped youngsters for elementary and secondary programs. Table 2 contains the calculations, based on actual cost data from Florida for 1978-79.[4] This figure is consistent with other reported costs such as $4,257 per year to educate a handicapped child in Pennsylvania in 1977-78 (Pennsylvania Department of Education, Note 9) but higher than the reported national average of $1,967 using the cost data of Rossmiller, Hale, and Frohreich in 1970, adjusted to 1978 for inflation.

**Proportions of Various Handicapped Children in Early Intervention Programs**

It is important to base a cost estimate on the actual proportion of handicaps within a given population rather than on national prevalence rates because a group of youngsters identified and served at an early age are usually more severely impaired than those whose handicaps are not identified until after entering first grade. The Texas Consortium reports the proportional incidence of various handicapping conditions found among 806 youngsters aged birth to two years enrolled in nine projects (Macy Research Associates, 1978). The proportion of primary problems were these:

| | |
|---|---|
| Mentally Retarded | 26.0% |
| Developmentally Delayed | 22.1% |
| Orthopedically Handicapped | 14.3% |
| Other/Physically Impaired | 17.1% |
| Language Problems | 9.7% |
| Auditory Problems | 3.9% |
| Vision Problems | 3.9% |
| Emotionally Disturbed | 3.0% |

[4]Florida cost factors were used for several reasons. The factors are based upon actual expenditures each year by area of handicap and have been in use for several years (Florida State Chapter 236.081, Funds for Operations of Schools). Also, Florida was tenth among states serving over 100,000 handicapped children in 1977-78 (U.S. Department of Health, Education, & Welfare, 1979). The report also indicated that 40% of these youngsters were multihandicapped.

In Table 2, these proportions have been used in Column 3 to estimate the actual numbers of youngsters in each category. It is important to note here that the differential cost factors for each handicapping condition will significantly affect the actual costs of education for any specified group of handicapped youngsters, depending upon the composition of handicaps within the groups.

Several adjustments between the Texas Consortium prevalence data and the Florida cost factors (Column 2 in Table 2) were made. Because Florida does not report a cost factor for "developmental disabilities," this Texas Consortium category was considered to be equivalent to the educable mentally retarded (EMR) cost category in Florida. Also, the Texas Consortium category of mentally retarded was considered equivalent to the trainable mentally retarded (TMR) cost category in Florida. Support for this adjustment is based on the assumption that severely handicapped infants are identified and served more often during the first years of life than those with less severe handicaps.

**The Proportion of Severe/Profound Handicaps.** Some estimate of severity of impairment is included in the cost calculations because of the likelihood that the more severely handicapped will continue to need higher cost education throughout their educational programs. In Table 2 (Column 4), a 20% estimate of prevalence of severe impairment was used and each area of handicap was reduced proportionately. This assumption of equal distribution of severity across the categories was based on a study of the levels of impairment of 805 handicapped infants at the time of exit from 16 randomly selected early intervention projects in the Texas Consortium in 1980. This study reported that 20% of the group were severely impaired. The ratings of severe functional impairment included these areas of development: motor, self-care, social, cognitive and language (Macy & Carter, 1980, Tables 13-17).

**Regular Education Costs.** An average annual cost per child of $1,148 for regular education was based on actual costs for the basic education program (K-12) in Florida for 1978-79. This cost is low when compared with the national annual per pupil expenditure of $2,060 (Smith, 1980) or with Pennsylvania's nonhandicapped pupil annual cost of $1,631 (Pennsylvania Department of Education, Note 10).

**Follow-up Programs For Early Intervention Program Graduates**

To obtain an estimate of the proportion of handicapped youngsters who no longer needed special education placements following early intervention, results from three studies were used.

**Graduates of Infant Programs.** The Texas Consortium reported that 12% of the handicapped infants exiting from special programs (birth through age two) were subsequently participating in regular school programs (including regular nursery and day care), and 88% were participating in some form of special program such as early childhood special classes, speech programs, resource-room programs and self-contained programs (Macy & Carter, 1980). These proportions were used in Table 1 to estimate the number of youngsters who might be expected to participate in regular and special preschool programs following an infant intervention program. One year (12 months) was reported to be the mean length of enrollment in such programs (Macy Research Associates, 1978).

**Graduates of Preschool Programs.** A sample of 940 handicapped preschoolers entering first grade was identified (DeWeerd, Note 11). All of these youngsters had received preschool programs from demonstration projects in the Handicapped Children's Early Education Program

(HCEEP). In this group, 525 (55.8%) were able to enroll in regular education programs and 415 (44.2%) enrolled in special education programs following early intervention. These proportions were used to estimate the number of youngsters who might be expected to participate in regular and special elementary programs following special preschool programs. Because this particular sample is among the first group of preschool handicapped youngsters to have received services, it is unlikely that the children would have received more than four years of special preschool intervention.

A subsequent third-party evaluation of HCEEP projects by Battelle Research Institute had similar findings (Stock, et al., 1976). The Battelle study reported that for 125 randomly selected children from 32 HCEEP projects, the median age at entry was 49 months. This study reported that approximately two-thirds of the HCEEP project graduates were placed in regular school classes, and the teachers reported that 89% of the children were appropriately placed. The decision to use the lower rate (55.8%) for regular school placement was an attempt to correct for this error in placement for 11% of these children.

**Graduates of Elementary Programs.** Estimating the proportion of handicapped youngsters leaving elementary programs for regular and special secondary programs was difficult because no data were available. An arbitrary estimate was made of one-third (33%) into regular education, one-third into partial services and one-third into full-time special education. These two latter categories were collapsed into an estimate of 67%, because youngsters who remain in need of special educational or related services at the secondary level are likely to be the more severely impaired and, therefore, a lower proportion would be entering regular education with no further special needs.

## Summary

The preceding cost figures were presented to provide a beginning study of cost effectiveness for early intervention for the handicapped. While available cost data are limited, several studies have made important contributions.

The Texas Consortium (Macy Research Associates, 1978; Macy & Carter, 1980) provides an opportunity to study the results of infant intervention with a large group of handicapped infants. Third-party evaluation by the Battelle Research Institute (Stock, et al., 1976) provides data about the impact of the Handicapped Children's Early Intervention Project (HCEEP) on randomly sampled handicapped preschool children from early intervention projects. Evidence of the long term cost benefits of early intervention also comes from Handicapped Children's Early Education Programs (HCEEP), Division of Innovation and Development, Office of Special Education (formerly Bureau of Education for the Handicapped). Progress reports from HCEEP projects showed that many children graduating from early intervention projects were able to enter regular education programs and thereby avoid more costly special education placement. In addition, many children graduated from HCEEP projects to programs which could not have accepted these same children before they had special help. Others were able to benefit from existing special programs in which they were previously unable to participate (DeWeerd, Note 12). A number of other similar reports were reviewed earlier in the "Impact on Children" section of this monograph. These reports indicate efficient and successful early intervention programs for handicapped children, resulting in benefits to the child, the family and the taxpayer. Clearly early intervention is cost-effective, developmentally for the child, emotionally for the family, and financially for the family and the taxpayers in the community.

## SECTION IV

## COMPREHENSIVE SERVICE PROGRAM

We have described the rationale for early intervention by documenting both the cost benefits of early intervention and the positive ramifications of early intervention on the quality of life for handicapped children and their families. We have asserted that early intervention is an essential, cost-effective initial step in a program of comprehensive services, which optimizes the developmental potentials of individuals with special needs and which minimizes their need for special services in the later years of their childhood or youth. If our society is sincere in its commitment to individuals with special needs, it must provide a continuum of services beginning with intervention at the earliest age for very young children and their families.

We realize that the present trend of fiscal restraints and reductions in funding for many federally supported programs, especially for education and human services, will no doubt have an impact on early educational services for handicapped children. Before any expansions in educational services for the birth to three handicapped population can realistically be accomplished, educators, parents and other professionals concerned about the welfare of young handicapped children need to advocate and lobby for the preservation of existing services. Dale Gentry (1981) summarized this point in his recent article, "Effectiveness, Efficiency and Advocacy of Early Education Programs in Times of Fiscal Restraint":

> . . . advocates must (also) create broad public awareness of support for early intervention programs. At the same time, they must become the activists who present the case for handicapped early education to administrators, school boards, legislators and others who are in decision making roles. (p. 2)

In the last ten years, there has been a steady increase in federal and state support of all educational programs for handicapped children. Especially since 1968, when the Handicapped Children's Early Education program was started and supported through federal seed funds, we have witnessed an expansion of infant learning and preschool programs. Even though the foundations for the provision of services to handicapped children from birth to age three have been established, much remains to be accomplished. At this time of fiscal restraints, administrators and legislators are cutting funding for early education programs in order to reserve limited funds for basic program needs. Gentry (1981) points out that "School boards, administrators, and legislators are reluctant to spread already limited funds to include yet another population" (p. 2). Therefore, now more than ever before, advocates for early and continuing educational programs for handicapped children and their families face a new challenge. Advocacy for services for handicapped children from birth to age three are especially important as this population was excluded from Public Law 94-142. "To deny them the attention that might increase their chances for improved functioning is not only wasteful, it is ethically indefensible" (Hayden, 1979, p. 510).

In view of this challenge, we propose the following recommendations as the ultimate goals of an early childhood comprehensive service program. Inevitably, our recommendations are somewhat ideal; yet this is a germane usage of the documentation we have provided. By evaluating our progress, taking steps to maintain our advancements and planning for the future, we both substantiate our past and give guidelines to look towards the future.

A comprehensive service program encompasses four areas: early identification, effective health care and educational practices, ongoing research and evaluation, and administration. Each of these concepts will be examined separately.

**Early Identification**

Services to handicapped infants and their families will promote the development of these infants and the functioning of their families during the succeeding years. We have demonstrated the importance of providing this intervention at the earliest possible time in the child's development. If we are to facilitate the development of these children in an effective and cost-efficient way, then we must have a systematic, transdisciplinary effort to identity children at risk or with handicapping conditions at birth or before. Moreover, this effort must offer periodic reassessment to plan appropriate services and to follow up those infants whose handicapping conditions could not be discerned at birth. If no system of early identification is implemented, interventionists will be dealing not only with primary, but with secondary handicapping conditions in children and with the increased stress of the children's families.

One of the first objectives in establishing comprehensive early identification systems falls within the range of general awareness of normal child development and handicapping conditions on the behalf of parents, educators and health care specialists, including pediatricians, clinical Intensive Care Nursery (ICN) nurses and other medical personnel. Parents, as the primary decision makers and caregivers, must receive support in their parenting efforts, information on the nature and extent of their child's handicapping condition, and how to cope with their added responsibilities. Medical professionals who deal with families and children, because they are frequently the first source to whom parents turn and the first to interact with infants with special needs, must receive training in identifying handicapping conditions and should be certified and licensed according to their training. Furthermore, they must develop an understanding of the signal importance of intervention and the success documented thus far in order to coordinate the child with appropriate service providers. Early identification is of no avail unless services or referral to services are available to the child and his or her family.

**Effective Health Care/Educational Practices**

Facilities must be available for transdisciplinary teams to offer, optimally at one site, services including audiological, speech and language services, neurodevelopmental services and physical therapy. In addition, some but not all families may require genetic counseling, nutrition services, outreach/child find, and psychosocial services, to include child psychiatry, social work or special day care. Other essential services which must be included in a comprehensive service program are medical and dental care and other relevant health care specialist services. Where all services are not provided under the direction of one center or agency, one professional or agency must take the responsibility for information referral and case coordination. For the families, respite care, transportation, legal counsel and advocacy support are also required in many cases.

When thinking of services, it is important to consider that all services must correlate to the nature and extent of the child's handicapping condition, his or her available support systems, family values, cultural preferences and financial resources. Furthermore, the services must be continuous in order to meet the changing needs of the family and the child; at one point a child may require extensive services, at another less extensive. Because child development progresses in discrete but interactive stages and each stage brings to focus a particular physical, social/emotional or cognitive skill, handicapping conditions, most of which

pervade all areas of the child's development, manifest themselves variably according to the particular stage of development the child is passing through. These manifestations of the handicapping conditions give rise to changing needs over time. Thus, the handicapped child may require a variety of services throughout his or her development, especially if intervention begins late enough that secondary handicapping conditions have developed.

To reap the maximum benefit from early intervention and, in many cases, to prevent the actual onset of a potential handicap, the service providers must meet the needs of the family. Health care and other professionals must be sensitive to the special needs of handicapped children and their families. As we have seen in the previous section on families, the family of the handicapped infant should be strengthened so that it can satisfactorily perform its manifold responsibilities. Where special parenting skills are needed in order that parents may fill these roles, a comprehensive delivery system should provide the services needed to help parents develop appropriate skills and expectations. In order to do this, the needs of the family-infant unit must be assessed rather than only the needs of the child. Some services will be required by siblings as well as by the principal caretakers. Finally, the interventionists must keep in mind that the family has the right to refuse to participate in or to accept only parts of the services which they recommend. In the infant programs, parents should have the opportunity to assume a variety of roles including serving as members of advisory boards, as teachers of their children and as educators of other parents. In addition, parents must become members of the team which assesses their child's development, writes intervention plans and participates in intervention. They may also find support in becoming advocates for the handicapped and disseminate information about available services for young handicapped children and their families.

**Ongoing Research and Evaluation**

A review of the current state of the art in early intervention suggests the need for definite research in specific areas. Encouragement for this research has come from the Office of Special Education, the National Institute for Handicapped Research, the HCEEP Early Childhood Institutes, Maternal and Child Health, Developmental Disabilities, and the National Institute of Health. It is hoped that research support will continue to be made available through these and other agencies. Moreover, to avoid duplication of local and state efforts, funding for research should be coordinated by a federal agency.

Thus far, federal programs supporting research in mental retardation and handicapping conditions have led, not only to improved practices, but to prevention. The knowledge accumulated from early childhood research institutes, universities and other federally-funded research centers, especially that which has come from the remarkable progress in the last five to ten years, has benefited our society as a whole. Knowledge about RH-incompatibility, Down's syndrome, Tay-Sachs disease, rubella, fetal alcohol syndrome and Phenolketonuria (PKU) has made it possible to reduce significantly the incidence of these conditions. Continued research of all handicapping conditions will no doubt result in similar positive reductions of incidence, ultimately meaning a reduction in the need for expenditures on services. Thus, while research leads to better practices by which we can eliminate or mitigate the deleterious effects of handicapping conditions, it also is showing us ways of preventing these conditions from occurring in the first place. Nevertheless, while much has been done, much more needs to be done.

Among the kinds of research needed are longitudinal studies using sound methodologies and collaborative research which crosses over agencies, institutions and disciplines. Priority areas for research are comparisons of the long-term effectiveness of different intervention models on the children served, family dynamics, health of the principal caretakers, and the

cost of additional services (e.g., special education, health, mental health, welfare) required by children with special needs and their families. In addition, studies are needed of the interaction patterns of families with handicapped or at-risk children, methods for measuring attachment/bonding patterns between parents and infants with special needs, and development and refinement of methods of early assessment and identification of handicapped and at-risk infants.

In order to improve upon present practices, we should continue to evaluate the effectiveness of different treatment strategies, such as sensory integration and neurodevelopmental treatment, in addition to evaluating the effects of parent involvement on the development of handicapped children and the family. As we have indicated, evidence suggests that involving families and parents more in the intervention programs for their children, as trainers, educators and advocates is having positive effects on the developmental and social/emotional future of the child and the parents; moreover, as the cost figures from the Texas Consortium study suggest (Macy & Carter, 1980), parents as teachers of their handicapped children affords the lowest cost services presently available to handicapped children.

**Administration**

The administration of a comprehensive service program is a key determinant of a successful network of services. Keeping to our proposal that continuous coordination of services to handicapped children is an essential component of both prevention and remediation of handicapping conditions, the administrative functions and interrelationships of local, state and federal agencies are mandatory to implement successfully comprehensive early intervention systems. We think that a few general recommendations can be made which should provide some direction and needed coordination among various agencies. In view of this, local, state and federal administrative levels are examined separately below.

Local Level. A number of structural or functional models may be used at the local level in a comprehensive delivery system. In metropolitan areas, all services may be provided in close proximity to each other or at one center. In sparsely populated areas, the services of some specialists may be offered at two or more sites. Funding may be obtained from the private and/or the public sector. In any model which is used, the services should be accessible to every handicapped or at-risk child and his or her family, and procedures should ensure the following:

1. Planning and service delivery which is coordinated through interagency agreements
2. Parent representation at the level of policy development
3. Ongoing evaluation of child progress
4. Ongoing evaluation of program operation
5. A centralized referral system and directory of services and service providers

State level. Despite the important legislative and administrative involvement of the federal government within educational systems, the implementation of educational services or practices remains largely the responsibility of each state. While variability in programming among states is both to be expected and encouraged, some coordination among states is also

necessary to eliminate the duplication of research efforts, administrative planning, and testing of best practices. Some recommendations which may facilitate this uniformity within diversity follow. Each state should have:

1. Comprehensive state plans, developed by a lead agency or governor's committee, which include interagency agreements defining specific agency responsibilities for the funding and the operation of a comprehensive service delivery system comprised of programs and agencies in the private as well as the public sector for handicapped children from birth to age three (or to the age mandated for educational services)

2. Guidelines and procedures to ensure program accountability and to achieve the comprehensive service delivery goals

3. Periodic cost analysis and impact studies for the purpose of identifying the most cost efficient and cost effective/quality models of service delivery

4. A multiagency mechanism for the continuing education of all service providers, with emphasis on interdisciplinary and transdisciplinary training

5. An advocacy board on infancy with a membership composed of a) representatives from agencies serving children, b) parents and c) professionals from education, health, allied health and social services

Federal Level. Over the past few decades, the role of the federal government has been to provide incentives for basic and applied research in early childhood special education, for the dissemination of information and for teacher education. With the passage of P. L. 81-164 and P. L. 94-142, the government extended its incentive initiative into encouraging states to make special education services available to those handicapped children and youth who at that time were either underserved or unserved. Moreover, programs such as the Handicapped Children's Early Education Program (HCEEP) originated as a result of federal legislation; through these programs, the federal government awards seed money which projects use to initiate, develop and then disseminate exemplary and tested programs for handicapped children and their families. Thus, the federal government's role has been extended to the validation and promulgation of best practices in special education.

While we remain optimistic that the role of the federal government to administer fiscal resources as impetus to research, information dissemination, and stimulation of best practices will continue, we do see a greater need for an increased collaborative and cooperative effort at the federal level among leaders in education, health care and government. A national policy is needed to ensure that fiscal resources are appropriately distributed, that educational practices are rigorously validated and that all handicapped infants and children are capably identified and effectively served. Because all persons, handicapped and nonhandicapped, stand to benefit from the child development research, prevention practices, and educational practices discovered and developed through such a comprehensive program, the spin-off advantages will offset initial expenditures by increasing the quality of life for all. What is needed is the federal support of a national policy for early childhood special education, developed in collaboration with health care and special education professionals who can communicate effectively with the appropriate federal, state and local legislators to keep them informed of new findings and practices in education and care for the handicapped. Such a policy should lead to legislation designated to provide incentives for states to set up a

comprehensive service delivery program to those handicapped and at-risk children aged birth to three. Taking into account the benefits to the child of early intervention beginning at the youngest age possible, the importance of extending assessment and service follow-up to the family, and the cost savings to taxpayers when services provided early reduce the numbers of children requiring more expensive services later, this national policy should ensure that early identification of handicapping and at-risk conditions is practiced routinely, that tested follow-up, prevention and remediation services are guaranteed to those in need, and that families as well as children have access to these services.

Because such a national policy would oversee a broad population and cross over state and local regulatory boundaries, it should contain some provisions for coordinating research, health care and educational services, and administrative collaboration on a large scale. Some recommended steps would be to:

1. Support the role of families as the primary caregivers of their children.

2. Support the delivery of services which can prevent the development of handicapping conditions.

3. Facilitate interagency activities related to services for high-risk pregnancies and infants at risk.

4. Establish and maintain a voluntary National Advocacy Board for Handicapped Infants with Special Needs.

5. Initiate a mechanism to fund transdisciplinary training for professionals, paraprofessionals and parents in skills related to the support of the development of young handicapped children

6. Establish Regional Technical Assistance Centers to provide technical assistance to programs serving infants with special needs and their families

7. Set up or identify a national organization to collect and disseminate data on infant intervention, such as incidence figures, demographic data and research findings

Through a national policy coordinated with state and local programs, we can ensure that handicapped individuals and their families receive the continuum of services they need. As we have shown, any such continuum must begin with services for the child at birth, the most propitious time for beginning intervention. Delaying intervention is costly -- for the child, for the parents and for the taxpayers; beginning intervention early reduces these human and financial costs, and is an essential, cost-effective initial step in the process of integrating individuals with special needs into the mainstream of society.

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